

# Knowledge *Into* Action

## Event Report



A report on the proceedings of *Knowledge into Action*, held February 14<sup>th</sup>, 2019, in the LexIcon, Dun Laoghaire, jointly hosted by the **DLR-Drug and Alcohol Task Force** and **Southside Partnership**, with funding from **Healthy Ireland**.

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## Introduction

The workshop was conceived and developed to promote collaboration across key agencies and community members in addiction and child and family services. Organised by the Dun Laoghaire Rathdown Task Force (DLR-DATF) Treatment and Rehabilitation Committee (T&R) the event was focused on bringing together people from different domains, backgrounds and organisations alongside community members and service users. The overall purpose of gathering people together was to improve health and social outcomes for drug service users and their families by fostering interdisciplinary engagement. Eighty participants attended.



In his introduction, Dr. Barry Cullen, DLR-DATF coordinator, outlined the underlying theme of collaboration that would run throughout the *Knowledge Into Action* event. Whilst policy was mentioned as important, the key focus for discussion was improving practice in the field for and amongst practitioners and service users. The values of hope and positivity were presented as at the core of working together successfully. These were linked to trust and it was hoped that discussion at the event would foster further trust-building between service providers and also between services, their users and the community. It was noted that there was a broad range of people from different backgrounds, some of whom had not attended DATF events before, allowing the event to build on and foster further a culture of trust.

Belief in the ability to overcome the problems that lead to drug and alcohol issues was identified as key to real improvements. Improved relationships (between different services as well as between service user and

practitioner), housing and access to services were highlighted as critical factors that need to be addressed to enable individuals to overcome problem alcohol and drug use. This holistic approach would be brought up repeatedly throughout the day and is crucial to multidisciplinary collaboration. Barry ended his introduction with an invitation to participants to listen without being defensive or blaming; reflexivity would help build alliances.

## Workshop A: Overcoming the stigma and secrecy associated with long-term drug treatment

The session was informed by a presentation by Dr. Paula Mayock whose report, *Just Maintaining the Status Quo?: The Experience of Long-term Participants in Methadone Maintenance Treatment* (2018) written jointly with Shane Butler and Daniel Hoey, was the first of its kind in Ireland. Paula stressed that this was a small-scale, exploratory study and that further research is needed, but the findings about the difficulties long-term methadone users encounter provide insight into the many challenges they face. Stigma was a cross-cutting theme throughout the research and presented major problems for the ageing drug treatment population. Despite older drug users being recognised as a group with distinct needs in policy, their lived experience was marked by discrimination in multiple aspects of life.

Participants in the research had accessed drug treatment for the first time at least ten years prior to the study. They were recruited from addiction and housing support services across the Dun Laoghaire-Rathdown area. Open-ended, qualitative interviews were conducted with 25 people with an emphasis on services users telling their own stories.

They generally had low educational attainment and the majority were (long-term) unemployed, relying solely on social welfare payments for their income. Homelessness was a current/past problem for more than half of participants, particularly men. They also reported a lack of supportive social ties and relationships, in terms of family, friends and a wider sense of 'community'.



The presentation highlighted three categories of stigma experienced by long term Methadone Maintenance Treatment (MMT) users:

Institutional stigma is perpetuated by organisations. This is often covert but can lead to clients not being prioritised for housing, for example.

Everyday stigma is perpetuated by family, friends and the wider neighbourhood.

Lastly, self-stigma is internalised and can lead to self-isolation and low self-esteem. Self-stigma had a gendered element as women were more likely to report being particularly conscious of the need to keep their methadone use a secret and of their appearance, referring to, for example, dental problems that can occur with long-term methadone use.

These categories were described as traumatising and presented barriers to engaging with services. The study found that participants had an 'all-or-nothing' approach to service engagement, either tending to be accessing multiple services or none at all. Women were more likely to be using no services, potentially linked to their desire to keep their methadone status a secret and thus compounding their isolation. Paula noted that stigma is silent with the stigmatised often having few opportunities to speak about it and that they only did so in this research because they were specifically asked about the topic.

In the discussion immediately after the presentation, the consensus was that the

findings spoke to the reality encountered by people working with long-term service users. One attendee suggested that people on methadone are potentially institutionalised themselves, which links the idea of self-stigma to institutionalisation. Several people highlighted the gendered element of the findings and whilst they supported services specifically for women they were worried that stigma would be a barrier to attending such services.

Group discussion was facilitated by John Doyle from the DLR Community Addiction Team. Attendees considered the warm-up question 'How does what you have heard connect with your experience of working with people who have been in long-term treatment?'. Those working with this client group felt that the report's findings mirrored the experience of their service users closely. However, there was some debate as to whether there was actually the lack of services and the kinds of attitudes in the methadone clinics that participants described with one attendee contending that the participants had not provided an accurate portrayal of HSE services.



Further questions focused on obstacles to better collaborative working between agencies to overcome stigma in treatment and how these could be overcome. It was felt that the current HSE model of dealing with addiction was too medical and drug-focused. Several attendees argued that this was the wrong framework and that the lack of a holistic approach was a major obstacle to agencies working together. The institutionalisation of staff in clinics was mentioned as another obstacle as was a lack of knowledge by professionals about the range of services on offer.



Ways to overcome these obstacles centred on a multi/interdisciplinary approach with clarity over the services that are available. Centrally collated data was also mentioned so that patient pathways could be better understood, although there was recognition that this would need increased funding.

Although attendees identified several obstacles to interagency work, there were also many, varied ideas generated as to how these could be overcome. This spoke to the vision of hope and trust as there was a willingness, and indeed wish, for people from different agencies to work together. Generally, there was an acceptance of the research findings and people appeared empathetic and had multiple ideas about how to make improvements, although it was acknowledged some of these would require significant funding and willpower.

### **Workshop B: Working collaboratively across both drug and alcohol and child, family and other services**

This workshop commenced with an input from Mary Daly, Project Manager, Barnardos, DLR. Barnardos operates a DATF-funded service that is focused on supporting parent-child relationships in families where parental substance misuse has become an issue in family functioning or child development and wellbeing. The service relies on collaboration across a range of child/family and addiction services in order to get it right for both children and parents. A Túsła led collaborative interagency model was illustrated using a case study of a 9-year old with behavioral and child safety difficulties and a family history of drug misuse and family bereavement, who was assisted through the inter-agency approach which saw multiple services provide him, his school and his family with support. This successful example of services working together to help a vulnerable family showed that interagency work is achievable and promotes positive change. The input had an audio-visual dimension, thereby illustrating visually the limited choices available to the parent and child when services existed in isolation, but similarly, visually highlighting how positive outcomes improved dramatically when

different services worked closely together, keeping the child as well as the parent in focus.



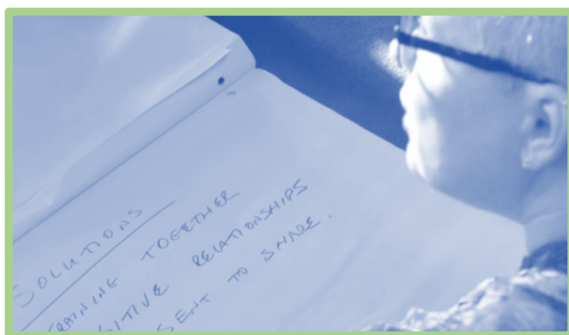
The workshop also drew from the joint HSE/Túsła national *Hidden Harms Project* with a focus on the impact drug and alcohol abuse can have on children and families. Caroline Jordan from Túsła, who is involved with the *Hidden Harms Project*, outlined issues that arise in attempts to support multi-agency work amongst professionals in the field. She spoke about how harm suffered by children is especially likely to go unnoticed or not to be considered harmful even if it is visible.

It is intended that the project will tackle the hidden harm that can be caused by alcohol and substance use within families with an estimated 587,000 under-18s in Ireland thought to be exposed to risk from hazardous parental drinking. A gulf between substance/alcohol-related services and children's services has been identified but this can be addressed by services focusing on the collective needs of families rather than solely looking at individual components.

Whilst it was acknowledged that effective treatment of adults can hugely benefit children, it was argued that reducing harm to children should become explicitly central to drug and alcohol policy. Early intervention, and prevention were highlighted as of key importance to child wellbeing.

The break-out into small groups was facilitated by Aoibhinn King from the HSE. Similarly to Workshop A, the questions discussed in groups focused on barriers to interagency work and how to overcome these to improve social reintegration. Obstacles discussed included the lack of training on

addiction provided for social workers. Several felt that they were working without the ‘full facts’ and lack of communication (exacerbated by GDPR) and knowledge of services available were repeatedly stated to be problems. Funding and staffing were also mentioned as issues. Generally, it was felt that children’s voices are not centred – or even heard – often enough. There was also a gendered element to the problems discussed with some noting that women tend to isolate themselves and not access services as a result, suggesting that the gendered aspects of self-isolation and self-stigma that were mentioned in Workshop A have wider applicability.



Ideas to overcome these obstacles included promoting greater awareness of services, for example a directory of services – interesting given that this was also a suggestion in Workshop A, indicating the need for greater knowledge sharing. Consent to share was another proposal for fostering knowledge and communication. Training people from different organisations together was mentioned several times as a way to build positive relationships with participants, again reinforcing the importance of good relationships to facilitating knowledge sharing.

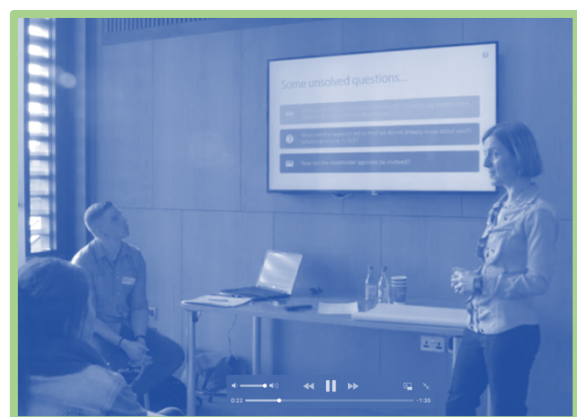
The workshop indicated that although there is a desire and willingness for greater collaboration between agencies there are barriers to communication and a lack of knowledge of the full extent of services available. Again, having a central, accessible database of services was touted as a first step to tackling these problems. Although considering a different client group, as with Workshop A there was a focus on listening to those whose voices are not always heard, in this case children. Listening to those that

services are designed to help was identified as key to improving social integration.

### **Workshop C: How young people view the use of mood-altering substances in their everyday lives**

Dr. Louise Kinlen presented her findings from an exploratory feasibility study regarding carrying out research on youth substance misuse in the Dun Laoghaire Rathdown county area. This initial feasibility study involved conducting interviews with key stakeholders and established that there was a desire for further research to better establish the dimensions of the problem. In response to this, the DLR-DATF is about to commission research into this issue which will address questions such as:

- Why are young people engaging in substance misuse (or why are they not)?
- What types of substances are most prevalent?
- Who is engaging in it?
- Where is substance use amongst young people most prevalent?
- What do young people themselves say about it?
- How do services respond and is it effective?



Currently, little is known about these questions and youth substance misuse in the area. What is known is that there are incidents of intergenerational substance misuse, although the problem is occurring across all populations with use starting as

young as ages eleven or twelve. Substance misuse amongst girls is more hidden – a notable point given that women isolating themselves due to stigma was mentioned in both Workshops A and B suggesting that this can occur from a young age and is an area that potentially needs interagency focus.

The workshop was facilitated by Barry Dempsey, Prevention Coordinator, from Southside Partnership. Questions addressed in groups of four or five focused firstly on the potential scope of future research, asking participants to think about what they wished to know about young people’s substance misuse or lack thereof and what causes it to become problematic. The issue of intergenerational substance misuse was picked up on as participants were interested to know about family history of drug use, echoing some of the issues discussed in Workshop B. Linked to this was a desire to know about parental attitudes to substance misuse. People also wanted to know more about young people’s decision to use drugs; what information they used to make their decision (including what information they took from drugs education), whether they enjoy using drugs and whether it is a conscious or unconscious decision. Regarding problematic substance misuse, people wanted to know at what point young people themselves recognised it as a problem. What young people consider to be addiction was also queried, illustrating an awareness that young people might have differing definitions of ‘problematic’ from practitioners.



Questions also focused on ideas for how to help young people express themselves and share their insights into substance misuse – a key concern as giving voice to young people is a central aim of the research. It was thought

that the relationship with researcher and young people was crucial for getting young people on board. How the conversation should be framed was discussed with acknowledgements that what young people like and enjoy about drugs should be a part of the conversation. Other suggestions included holding the interviews in environments familiar to research participants and keeping them informal. The possibility of making a short animation film with young people talking in the third person was also floated.

Parental consent was discussed in relation to the young research participants under 18. It is required for all young people under 18 and this was explained in the workshop.

The participants were asked about their role as practitioner researchers which was discussed – i.e. the practitioners (youth workers etc) assisting with the research. Many were open to this, with some caveats in relation to the objectivity of the data, how it may affect existing relationships, and the need for training in order to provide the support necessary. There were some concerns about whether practitioner research could have a negative impact on the study and the pre-existing relationship between researcher and research participant. Trust was identified as of crucial importance to enabling peer research as was thinking reflexively about the relationship and role of researcher. Further input is needed to understand what kind of training people want/need but initial ideas mentioned education on ‘what to look out for during research’.

The possibility of young people themselves being involved as peer researchers was also suggested, through means such as making a short animation film. This would require further ethical investigation.

The workshop highlighted that there is an appetite to learn amongst service providers with questions about what people ‘don’t know but would like to know’ generating much discussion. There was a recognition that in order to find out the answers to these questions it is crucial to listen to young people themselves and take what they say seriously, illustrating openness to knowledge sharing where learning comes from service users and



community members. This pertained to the theme of trust as the proposed research is reliant on young people trusting the researcher and trusting that their voice will be heard. As with the other workshops, building and maintaining relationships emerged as a necessity for enabling successful knowledge production and sharing.

### Plenary presentation 1: Saving lives through awareness, implementation and treatment



Representatives of Community Response (CR) and Hepatitis C Partnership delivered a presentation on their work on awareness, testing and treatment of hepatitis C. The ethos of community development that has been at the heart of Community Response since its foundation in 1990 informed their work on hepatitis C as did their experience of working with long-term drug users.

The first section of the presentation focused on information and awareness. Many of the clients who were long-term drug users reported being told by clinical staff that they were 'lucky' not to have HIV and thus had pushed their hepatitis status to the back of their mind. There was also an element of fear in engaging with treatment, especially for stigmatised populations who may mistrust clinicians. To combat this CR and the Partnership engaged in psychoeducation targeting low-threshold services as sites for education. They found that amongst people who use drugs there was a lack of basic knowledge about hepatitis C. Some participants did not know there was a cure, confused the virus with HIV by thinking that it could develop into AIDS and there was a

general lack of understanding about transmission.

CR and the Partnership went on to outline the work they had undertaken on treatment. Treatment was being moved out of hospitals and into community centres thereby making it more accessible in some respects. However, it was still not accessible for those with certain comorbidities who have to be treated in hospital. In response to this problem, the peer support service *Hepfriend* was developed in conjunction with the Mater hospital in Dublin. By linking people who have or are at risk of having hepatitis C with a peer 'buddy', the project was designed to make seeking healthcare less daunting and reduce the stigma around the illness. *Hepfriend* created a new pathway for treatment as people did not have to get a referral from their GP for testing and treatment but rather could be referred directly through the scheme, meaning that a different and quicker pathway opened up. The case study of Stephen provided the example of someone who had used drugs for a long time, was unaware of the care he could receive and was given a tailored care plan through *Hepfriend*. However, the presenters outlined that were still issues with the overall effort to eradicate hepatitis C (as is the government aim by 2026) due to a lack of integrated, coherent plan across different domains.

It was pointed out that testing has come a long way. The *Swab to Tab* 2018 initiative was featured in the presentation as was the importance of testing for at risk communities. This initiative involved bringing the cure to these communities by testing onsite and then offering an appointment time for the hospital there and then. Funding issues were identified as barriers to the continuation of this service, reiterating the discussion throughout the day about how lack of funding impedes a holistic approach even when there is a drive to improve services.



A question after the presentation brought up the issue of geographical inequality in access to treatment, asking whether it is realistic to expect hepatitis C to be eradicated in communities outside urban areas such as Dublin. The presenters agreed that the outreach is not necessarily available with the most vulnerable not being reached. This was particularly the case in smaller towns and cities where the structures are not in place to help stigmatised populations. However, they restated their previous point that due to the lack of a coherent, integrated plan they felt that eradication of hepatitis C was not currently realistic in urban areas either. One attendee contested this, saying that in the area he practices medicine they have had an extremely successful drive to treat hepatitis C in nearly all cases.

Another question from an attendee involved in working with long-term drug users asked who was deemed suitable for hepatitis C treatment. The presenters answered that although people who had been perceived to be unstable may have previously been denied treatment it was now available to all.

The event tied in to other cross-cutting themes of the day as it was clear that those with the most complex needs and/or the most experience of stigma were those hardest to reach for hepatitis C education, testing and treatment. However, it was also an informative and hopeful session which highlighted innovative ways in which community and medical organisations can work together to tackle challenges faced by long-term drug users. After the discussion of the workshops, it provided a concrete model of CR, Hepatitis C partnership and the Mater hospital successfully collaborating to help people who had often been ill for a long time

and/or faced multiple barriers to accessing treatment. This relied on trust between service users and services but also between services from different disciplines. It was helpful to have a model of how this could be done and how the values highlighted at the beginning of the day could translate and turn knowledge into action.

### **Plenary presentation 2: A human rights based approach to service user participation**

The presentation on a human rights based approach to service user participation was facilitated by Cecilia Forrester from Community Action Network (CAN) who described how this approach is informed by social, economic and cultural rights. Whilst rights are broadly recognised they do not always accord with needs and stigmatised individuals like people who use drugs are likely to encounter structures that perpetuate inequality. A human rights approach places people at the heart of change with rights holders having input into how they want their rights to be realised. Again, the importance of listening to and learning from the lived experience of service users was highlighted – particularly given the unequal power relations which mean their voices are not always heard.



Although legally services have to be human rights and equality compliant, Emily Reaper, a representative from Service Users Rights in Action (SURIA) spoke about how she felt service users' rights were still being contravened. This project supports the active involvement and leadership of service users and recently published the *Our Life, Our Voice, Our Say* (2018) report looking at the



experiences of methadone patients. The presenter highlighted four key areas where human rights and equality was not being prioritised for this population:

- Supervised urine testing was described as “innately wrong” by the presenter (particularly as the client group are more likely than the general population to have suffered previous trauma/abuse). Clinicians have been directed to move away from this practice but it continues to be used.
- Lack of meaningful engagement on the part of the HSE. Service users felt that they were not listened to.
- The lack of a clear, transparent and independent complaints process for methadone patients. As this group are so stigmatised this was felt to be of even greater importance than usual as they have no recourse in the media due to the lack of sympathy usually afforded to them in public discourse.
- The lack of real treatment choice and participation. It was emphasised that trust had to extend to service users and that they should have a say over their treatment, for example, whether they want their methadone dose to go up and down. Relationships between service users and practitioners need to be fostered to allow the former a meaningful say.

The presentation was concluded by Richard Healy, a PhD candidate at Maynooth University, who has conducted mixed-methods research with methadone users. He described how talking to people face-to-face has given him invaluable data, echoing what Paula Mayock described earlier in Workshop A. Similarly, he also spoke about how research could reduce passivity and give voice to people who usually do not have an (audible) voice. His methodology of co-created knowledge was especially interesting given the cross-cutting themes of the day as it positions service users as knowledgeable and people that can be learned from. The idea of co-created knowledge could potentially inform the upcoming work with young people on substance use.

## Q&A Session

Barry Cullen then thanked the presenters and noted that several contested issues with no clear solution had arisen over discussions throughout the day, before opening up to the floor for a Q&A session. There was significant praise from the audience for the presentation from SURIA. One medical professional agreed with their stance on urinalysis arguing that despite clinical decisions being based on them there was no peer-reviewed evidence base to support this. He proposed that they were still used because of a hangover from abstinence-based treatment where urine sampling was used as punishment. Raising once again the theme of stigma, he argued that the HSE stance towards this patient group is informed by morality and the view that heroin is an immoral drug.



Poor training for doctors was mentioned by a number of attendees with a medical background. An attendee asked whether Community Response and Hepatitis C Partnership can provide training, suggesting that the workshop had already proved fruitful with attendees keen to learn more. The representatives from these agencies provided details of training that they can provide for both staff and clients.

The issue of diverted methadone was raised by an attendee who was concerned that this could contribute to child fatalities. It was pointed out by panellists that diversion is not a problem specific to methadone and that diverted methadone can come from those who provide a ‘clean’ urine sample meaning that urinalysis does not end diversion. In fact, it can be a contributing factor as people will sometimes resort to buying methadone on the street as they dislike obtaining it from clinics

so much, with one panellist suggesting that they do not want to deal with 'nasty people'.

The social media details of presenters were asked for, again indicating a willingness to engage and continue the conversation. Comments were made recognising the lack of education in different sectors working with drug and alcohol abuse and there was a clear wish to learn from local projects and other organisations present.

## Conclusion



Despite there being some contention and disagreement, particularly around the role and involvement of medics in the treatment process, throughout the day there was an evident desire and commitment to work with others to improve, strengthen and turn knowledge into action. For most attendees, this extended beyond working with other practitioners to recognising how much there is to learn from service users themselves. Although there were expressions of frustration for those who have been trying to make improvements and partnerships in the sector for a long time, there were also signs of hope like the fact that several attendees had never been to an event on drug and alcohol use before.

Cross-cutting themes focused on stigma and discrimination and the severe effects this could have on people's lives, but action and solutions were also a focus with concrete examples of projects that had improved service users' lives and health.

Because there was a broad range of disciplines and services represented at the event it is hoped that going forward further cross-agency action will emerge to tackle the problems outlined. Although the event is just a starting point in this process, the tone of the day was optimistic and discussions happened between people who would not normally be in a room together.

## References

Community Action Network. (2018) *Our Life, Our Voice, Our Say*. Available at: [https://www.maynoothuniversity.ie/sites/default/files/assets/document/our life our voice our say report final 0.pdf](https://www.maynoothuniversity.ie/sites/default/files/assets/document/our%20life%20our%20voice%20our%20say%20report%20final%200.pdf)

Mayock, P., Butler, S. and Hoey, D. (2018) *"Just Maintaining the Status Quo?": The Experiences of Long-term Participants in Methadone Maintenance Treatment*. Dublin: Dun Laoghaire Rathdown Alcohol and Drug Task Force. Available at <http://www.dlrdrugtaskforce.ie/web-version-of-report.pdf>

*Special thanks for organising this event to Marie Kavanagh, Angela Lennon and Bríd O'Dwyer, and other colleagues in Southside Partnership and to Healthy Ireland for providing the funding that helped make the event a success. Further information: <http://www.dlrdrugtaskforce.ie> [dlralcoholanddrugs@gmail.com](mailto:dlralcoholanddrugs@gmail.com) 01-706-0125*